

## **Changing roles for people, research & medicine: where do we go from here?**

caBIG Plenary

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PAIR: Patient Advocates in Research

CALGB CARE: Committee on Advocacy, Research Communication, Ethics, and Disparities

UCSF: Center for Translational Research

### **Today's buzzwords**

#### Promises

- "Personalized" medicine
- Genetic testing/ molecular risk
- Better control
- Manageable

#### For all?

- Biospecimen collections
- Multiple risks per person
- What has to change?
  - Scientifically/data
  - Clinical trial/biospecimens
  - Socially/culturally
  - Access/costs/rationing

NOTE: 'cure' and 'chronic' are not realistic yet  
Hyperbole causes mistrust & worse!

### **Hype doesn't help**

- "Trastuzumab after Adjuvant Chemotherapy in HER2-Positive Breast Cancer." (Piccart-Gebhart MJ et al. Oct. 20, 2005, New England Journal of Medicine (Vol. 353, No. 16: 1659-1672)).
- "Drug Touted as Cure for Breast Cancer" (10/19/05 AP)
- "Clearly, the results reported in this issue of the [NEJM] journal are... revolutionary." ..Gabriel Hortobagyi, MD
- .."In 1991, I didn't know that we would cure breast cancer, and in 2005, I'm convinced we have." ..Dr. JoAnne Zujewski, Breast Cancer Therapeutics, NCI CTEP

### **"Cure..." Really?**

2009 Statistical estimates

Cancer cases in Women: 713,220

27% Breast = 192,570 + 2,030 men

Cancer deaths in Women: 269,800  
15% Breast = 40,470 + ~500 men  
Source: American Cancer Society, 2009

Great people, wrong message!  
Can cause mistrust that lingers

### **We need real results**

Data/information does not equal knowledge does not equal results

- The good news
  - More survivors
  - More discoveries
  - More expectations
- The challenges
  - Shrinking budgets/ higher costs
  - More regulation

Dangers of not doing this well...

- False +/-, other inaccuracies affect millions
- Un-validated biomarkers .commercial products
- Leaves some groups behind
- Wastes time, \$\$\$, erodes trust, and costs lives
- Business as usual won't work anymore

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### **Why do we make it so hard?**

- Lack of access to medical records (HIPAA)
  - Now with more eHRs in each doctor's office
- Multiple permissions in care AND in research
- Steer people away from research
  - Can't admit we don't know 'the' answer
- Dismiss patient questions as irrelevant
  - Lack of communication in 2010?
- Lack of genotyping/markers in clinical trials and care = fewer drugs that can help a defined set of people

## **E is for “Excellent” institutions or “Excellence” in them**

- Can be expedient, but extends to extremes...
- Elicits euphemisms, like
  - Elitism
  - Egotists
  - Empire-building
  - Erosion of trust
- Experience and Effectiveness mean more
- This is what people want
- Can get it everywhere (e.g. SMEs, etc.)
  - Please don't exclude others who exhibit these elements elsewhere

## **The view from caBIGgers...DATA is the goal!**

- Where is it, who has it, how to get it, when to use it, how to share, what it means, how to get tenure,...

## **Others' view (including patients and people)**

- Data is one of many tools
  - (e.g. images, blood tests biomarkers, etc.) to help identify options for
  - Treatment
  - Prevention
  - Care of various diseases that I, or my family, may get.
- Useful only if it is useable by me and whomever I give it to.
  - Think Facebook
- And protected against misuse.

## **It's not about DATA!**

- It's about NEW ANSWERS to old problems
- Goal
  - Improve results by anybody who can, wherever the data is; not document the same old way we do things.
- BTW, SMEs are NOT peripheral;
  - They are WHY you develop tools & services!
- Stop talking past each other and
  - learn to listen, empathize, and
  - meet the needs of others, especially PATIENTS

## **Traditional approach: a great divide**

- Research
  - Discovery reigns
  - Human subjects
  - Egotism, elitism & hoarding
- Infrastructure
- Medicine
  - See what sticks
  - Patients & care
  - Paternalism

## **New concept: no walls**

- In the -omics era, no one has enough patients
- Need multiple scientific fields
  - For research AND care
  - How to connect them in new ways?
- Patients/people are partners, not subjects
  - They will contribute to research AND
  - Want to benefit from knowledge for healthcare
    - For themselves and future family members
  - Personal access to all of their records is critical
  - Notice I didn't use 'consumer'?

## **SOA is so important to so many**

- Thank goodness we have a model & acronym!
  - Systemic sandtraps seek standard solutions
- We have to seriously study operational situations and create PRACTICAL solutions
  - Now, time to clean up caBIG's internal house
- Makes sense to patients & patient advocates
  - It should speed up delivery of better care
    - Show results first, then sell it!

## **What patient advocates in research do...**

- Challenge & ask questions about end results
- Discuss information flows (e.g. BAM + others)
- Help combat systemic problems, e.g.
  - Push for change in clinical trial development/delivery
  - Share information & education
  - Harmonize old regs w/new approaches; minimize inertia
  - Get buy-in from institutions on security, etc...
- For caBIG
  - Push for practical successes
  - MUST be accessible, deployable, and interoperable!
  - Must build in usability as a primary function
- Discuss new fields that affect caBIG
  - Patient-Reported Outcomes (PRO), etc.

## **Formula for success**

Data > Information > Knowledge > Analysis > Results

- Quickly! For people!
- Need new forms of working connections
  - Between fields, departments, institutions, SMEs
  - IT can make this happen – help us!
  - Engage patient advocates throughout process
    - We help connect the dots

## **Thank you**

- Patient Advocates
  - In PAIR (~200)
  - In SPOREs (~220)
  - In NCI CARRA (~170) and DCLG (15)
  - In Cooperative Groups (~80)
  - In FDA (~20)
  - Many others
- Experienced: for creating new opportunities
- New: for fresh ideas & energy
- And to those who made a difference before their deaths
- Research teams for
  - Dedication
  - Efforts
  - Collaborations

Thanks for all you do for cancer patients and their families  
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